II. Epidemiological Profile of HIV/AIDS in Seattle-King County

NOTE: Parts of this section have been excerpted from HIV/AIDS Epidemiology Profile for Community Planning, June 2001, the Monthly HIV/AIDS Epidemiology Report (published by Public Health – Seattle & King County's HIV/AIDS Epidemiology Unit) and the HIV/AIDS Epidemiology Report - 2nd Half, 2000 (published jointly by Public Health and the Washington State Department of Health). For more in-depth information about the epidemiology of HIV/AIDS in King County and Washington State, please refer to these and other publications produced by the aforementioned programs. Information can also be obtained on the Public Health website at www.metrokc.gov/health/apu.

A. Summary

HIV infection and AIDS continue to have a major impact on the health of King County residents. As of 10/31/01, 6,341 cumulative AIDS cases had been reported in King County. Of these, 3,650 (58%) have died. Between 6,000 and 9,000 residents of the county are currently estimated to be infected with HIV.

Fortunately, AIDS-related mortality has declined sharply in recent years due to a decreasing annual incidence of AIDS and the efficacy of new drug treatment regimens. In 1994, HIV/AIDS deaths ranked second behind cancer in the highest number of potential years of life lost before age 65 in King County. In 2001, that number dropped to the sixth highest.

The geographic distribution of AIDS in King County varies widely. The highest overall average annual AIDS rate is in Seattle (22.3 per 100,000 population). Within Seattle, rates range from a high of 99.1 in the Central Area to a low of 8.7 in North Seattle. It is important to note that there continues to be a significant decline in the overall average annual rate of AIDS in Seattle since the 1993-1995 epidemiology report, in which the average annual rate was 70.8 per 100,000 population.

The overall average rate for King County outside Seattle has also declined to 4.3 per 100,000 population. Rates range from a high of 8.7 in Bellevue to 1.2 in Southeast King County.

Gay and bisexual men continue to be the population most heavily affected by HIV infection and AIDS. Young gay men in their late teens and early twenties are at particularly high risk of infection. In King County, 79% of cumulative AIDS cases have been men who have sex with men (MSM), with an additional 11% among MSM who also inject drugs. While the proportion of AIDS cases that are gay or bisexual men has decreased gradually over time, the proportion of cases in women and people of color have increased.

African-American, Hispanic and American Indian/Alaska Native residents of King County are disproportionately affected by HIV/AIDS. People of color represented 11% of reported AIDS cases from 1982-1986; this figure has risen to 35% of reported cases in 1998-2000. Between 1997 and 1999, the average annual rate of AIDS in African-Americans, Hispanics and American

Indians/Alaska Natives was 36.0, 35.9 and 33.0 per 100,000 respectively, compared to 10.0 per 100,000 in whites and 3.4 per 100,000 in Asian/Pacific Islanders. Among women, this discrepancy was even greater: the rate of AIDS per 100,000 in African-American women was 17.3 and in American Indian/Alaska Native women was 7.2, versus 0.9 in White women.

B. Description of King County

Geography: King County is 2,128 square miles in size. While the county has only 3% of the state's land area, it is home to 29% of the state's population. King County ranks as the twelfth most populous county in the United States.

Seattle and the suburban cities: Eight of the 20 largest cities in Washington are in King County. Seattle (2000 population: 563,374) is the largest city within King County (2000 population: 1,737,034). The county contains 39 incorporated cities, which account for approximately 79% of King County's population. Thirty-two percent of county residents reside in Seattle, 47% in incorporated suburban cities, and 21% in unincorporated King County.

Racial composition: The overall racial composition of King County in 2000 was 76% white, 11% Asian/Pacific Islander, 6% Hispanic or Latino, 5% African-American, and 1% American Indian/Alaska Native. Between 1990 and 2000, more than half of the new residents in Seattle were Asians or Hispanics. The region's minority population is far more spread out in the suburbs than in the past. Bellevue has the largest proportion of Asians (17%) of any city in King County. The cities of Renton and SeaTac now have about the same percentage of blacks as Seattle.

Socioeconomic status: The median household income in King County is $49,000. Approximately nine percent of families are living below Federal Poverty Level, with persons of color being almost three times as likely as whites to be living in poverty. The poverty rate was somewhat higher in the city of Seattle, at 12%. Within the county, areas with the largest percentage of the population below poverty level were Central Seattle, Southeast Seattle, Auburn, and Southeast King County.

C. HIV/AIDS in King County: Distribution and Trends

The Seattle metropolitan statistical area (King, Snohomish and Island counties) ranked 56th in AIDS case rates among the 101 metropolitan areas in the United States with populations of 500,000 or more for cases reported between 7/99-6/00. In 1995, the Seattle area ranked 35th among these metropolitan areas. The rate of reported AIDS cases in the Seattle metropolitan area was 11.4 per 100,000 population for the period of 7/99-6/00, down from a rate of 26.1 in 1996.

King County has the highest rate of AIDS of all Washington State counties. Although King County has less than one-third of the state's population, two-thirds of the state's AIDS cases have been diagnosed and reported in King County residents. Since the mid-1980's, however, there has been a steady trend toward proportionately fewer AIDS cases occurring in King County. Only 52% of Washington State's AIDS cases occurred in King County in 1999, compared to 64% in 1993-94 and 75% in 1986-87.

AIDS cases and trends by gender: Of the total 6,096 AIDS cases diagnosed in King County through 2000, 5,803 (95%) were male and 293 were female (5%) (Table 1). Females as a percent of annual AIDS cases have risen over time in King County, from 2-3% in 1987-90 to 14% in 2000.

AIDS cases and trends by race/ethnicity: The majority of AIDS cases in King County have occurred among whites. However, in the past decade, people of color have been increasingly affected by AIDS, accounting for 39% of the reported cases in 1999, compared to 19% in 1992-94. African-Americans and Hispanics also account for a disproportionate number of cases relative to their population in the county.

AIDS cases were diagnosed among African-Americans for the three-year period 1997-1999 at the average annual rate of 36.0 per 100,000, 35.9 per 100,000 among Hispanics, and 33.0 among American Indian/Alaska Natives. Comparable rates are 10.0 for whites and 3.4 for Asians/ Pacific Islanders.

AIDS cases and trends by age: AIDS affects persons of a relatively young age. Almost half (48%) of all reported cumulative King County AIDS have been between 30 and 39 years old at the time of their diagnosis, 25% were 40-49 years old, and 17% were 20-29 years. A higher proportion of female (29%) than male (17%) cases was under 30 at the time of their diagnosis.

Pediatric AIDS and HIV disease in King County: A very low proportion of AIDS reports have been pediatric cases (defined as under 13 years of age at the time of AIDS diagnosis). As of the end of 2000, a cumulative total of 15 pediatric AIDS cases had been diagnosed and reported, accounting for 0.2% of cumulative King County AIDS cases. In comparison, the United States figure is 1.3%.

AIDS cases by mode of exposure: Among the cumulative adult/adolescent (13 years and older) male AIDS cases, 75% have been men who had sex with men (MSM), 10% are MSM who also injected drugs (IDU), 6% were heterosexual IDU, and 3% were associated with heterosexual transmission (Table 1). The route of transmission among King County adult/adolescent males remained relatively stable between 1987 and 1994. In 1995 through 1997, however, a higher proportion of cases (8%) were associated with IDU and a lower proportion with male-male sex (68%) compared to previous years. In 1999, the proportion of male cases attributed to same-sex sexual activity was 69%, with 11% attributed to MSM/IDU. Among the 293 King County adult/adolescent female AIDS cases, 138 (47%) were attributed to heterosexual contact and 76 (30%) were related to injection drug use, compared to 40% and 27% of all United States adult female AIDS cases, respectively.

Table 1. AIDS Trends in King County: Cases Diagnosed through 2000

Category	Cases Diagnosed In 1996		Cases Diagnosed In 1997		Cases Diagnosed in 1998		Cases Diagnosed in 1999		Cases Diagnosed in 2000[1]		Cumulative Cases Reported 1982-2000[2]	
TOTAL CASES	418		295		250		180		113		6,096	
SEX	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**	**No.**	**(%)**
Male	388	(93)	271	(92)	227	(91)	163	(91)	97	(86)	5,803	(95)
Female	30	(7)	24	(8)	23	(9)	17	(9)	16	(14)	293	(5)
RACE/ETHNICITY												
White, not Hispanic	307	(73)	202	(68)	162	(65)	124	(69)	69	(61)	4,882	(80)
Black, not Hispanic	53	(13)	41	(14)	46	(18)	27	(15)	26	(23)	632	(10)
Hispanic	36	(9)	31	(11)	30	(12)	21	(12)	16	(14)	374	(6)
Asian/Pacific Islander	10	(2)	9	(3)	6	(2)	3	(2)	1	(1)	117	(2)
Am. Indian/AK Native	12	(3)	12	(4)	6	(2)	5	(3)	1	(1)	91	(1)
AGE AT DIAGNOSIS (YRS)												
< 13	3	(1)	1	(<1)	0	(0)	0	(0)	1	(1)	15	(<1)
13-19	1	(<1)	1	(<1)	0	(0)	1	(<1)	0	(0)	12	(<1)
20-29	59	(14)	46	(16)	32	(13)	27	(15)	21	(19)	1,041	(17)
30-39	211	(50)	143	(48)	122	(49)	81	(45)	44	(39)	2,955	(48)
40-49	116	(28)	72	(24)	63	(25)	56	(31)	34	(30)	1,532	(25)
> 49	28	(7)	32	(11)	33	(13)	15	(8)	13	(12)	541	(9)
EXPOSURE CATEGORY[3]												
Male/male sex	286	(68)	186	(63)	159	(64)	117	(65)	64	(57)	4,600	(75)
Injection drug use (IDU)	35	(8)	15	(5)	24	(10)	16	(9)	15	(13)	346	(6)
IDU & male/male sex	32	(8)	34	(12)	23	(9)	16	(9)	12	(11)	623	(10)
Heterosexual contact	23	(6)	16	(5)	11	(4)	7	(4)	7	(6)	194	(3)
Hemophilia	3	(1)	3	(1)	0	(0)	1	(1)	0	(0)	30	(1)
Transfusion	0	(0)	3	(1)	3	(1)	1	(1)	0	(0)	53	(1)
Parent at risk/has HIV	3	(1)	1	(<1)	0	(0)	0	(0)	1	(1)	14	(<1)
Undetermined/other	36	(9)	37	(13)	30	(12)	22	(12)	14	(12)	236	(4)

[1]Provisional data due to reporting delays
[2]Cumulative cases in King County residents meeting the 1993 CDC surveillance case definition of AIDS diagnosed and reported as of 12/31/00; includes cases diagnosed prior to 1993
[3]Cases with more than one risk factor other than the combinations given are tabulated only in the category listed first

Comparison of AIDS in Seattle and the rest of King County: Among the 6,096 cumulative AIDS cases diagnosed through 2000, 82% resided in the city of Seattle and 18% lived in other areas of the county. Compared to Seattle residents reported with AIDS, those living outside Seattle were more likely to be female (10% versus 4%), and to have been exposed through injection drug use (8% versus 5%) or heterosexual contact (7% versus 2%).

Estimated number of people with HIV in King County: Between 6,000 and 9,000 King County residents are estimated to be infected with HIV, including more than 2,500 persons living with AIDS (Table 2).

Table 2. HIV+ Estimates of Selected Populations in King County, 2000

CATEGORY	MIDPOINT		RANGE
	Number	Percent	Number
GENDER			
Male	6,825	91%	5,460 – 8,190
Female	675	9%	540 – 810
AGE GROUP			
<13 years	45	<1%	35 – 55
13 – 19 years	95	1%	75 – 110
20 – 29	1,725	23%	1,380 – 2,070
30 – 39	3,525	47%	2,820 – 4,230
40 – 49	1,650	22%	1,320 – 1,980
50 and over	450	6%	360 – 540
HIV EXPOSURE			
Male/male sex	5,250	70%	4,200 – 6,300
MSM/IDU	750	10%	600 – 900
IDU Heterosexual	525	7%	400 – 650
Heterosexual	375	5%	300 – 450
Pediatric exposure	45	1%	45 – 55
Other/unknown	525	7%	420 – 630
RACE/ETHNICITY			
White	5,500	74%	4,440 – 6,660
Black	1,050	14%	840 – 1,260
Hispanic	600	8%	480 – 720
Asian/Pacific Islander	150	2%	120 – 180
American Indian/AK Native	200	2%	120 – 180
KING COUNTY TOTAL	**7,500**		**6,000 – 9,000**

HIV/AIDS-related mortality: As of 10/31/01, 6,341 cumulative AIDS cases had been reported in King County. Of these, 3,650 (58%) have died. From 1995 through 1999, the number of AIDS-related deaths in King County declined dramatically. This decline averaged 50% per year between 1995-97. Deaths due to AIDS peaked in King County in 1995 at 439, but fell to 280 in 1996, 102 in 1997 and 88 in 1998. In 1999, only 51 deaths were reported. However, preliminary data from 2000 suggest that there may have been a slight increase in AIDS deaths during the year. The net result of the changes in deaths and AIDS incidence is that the number of persons living with AIDS continues to increase. As of 3/01, 2,600 King County residents were living with AIDS as compared to about 1,750 in 1995.

Persons living with HIV/AIDS: HIV case reporting in Washington State was implemented on September 1, 1999. In the eighteen months between 9/1/99 and 3/1/01, a total of 310 newly diagnosed HIV (non-AIDS cases) were reported in King County residents. HIV (non-AIDS) case reports have also been received for 1,594 persons currently receiving health care who were diagnosed with HIV prior to the implementation of HIV reporting on 9/1/99. These include King County residents reported as having progressed to AIDS and not known to have died. In addition, 2,600 persons living with AIDS had been reported and are not known to have died, resulting in a current total of 4,118 King County residents living HIV/AIDS reported to Public Health.

The epidemologic profile of the recent HIV cases is likely to better characterize recent HIV transmission patterns compared to AIDS cases or persons infected less recently and currently living with HIV/AIDS. Compared to persons currently living with HIV/AIDS, the 310 King County residents with recently-diagnosed HIV infection are more likely to be:

- Female (16% versus 9%)
- African-American (19% versus 14%)
- Hispanic (12% versus 8%)
- Currently less than 30 years of age (26% versus 7%)

By HIV exposure category, a larger number and proportion of female cases are attributable to heterosexual contact compared to males (38% versus 1%), as well as injection drug use (27% versus 5%). Females living with HIV/AIDS also tend to be younger (17% are ages 13-29 as compared to 5% of males) and more likely to be African-American (39% versus 11%) or Native American (5% versus 1%). The proportion of Hispanics and Asian/Pacific Islanders living with HIV are similar for males and females.

III. Methods

The needs assessment process used several strategies to gather input. The centerpiece of the process was the creation and distribution of written surveys to persons living with HIV/AIDS (PLWH) throughout King County. Other components of the needs assessment process included a written service provider survey, focus groups of targeted consumer sub-populations and key informant interviews with service providers.

A. Consumer Surveys

The 2001 consumer survey targeted persons living with HIV/AIDS throughout King County. The survey was based on ones developed in previous needs assessment processes. (See Appendix D for a copy of the consumer survey instrument.) The HIV/AIDS Planning Council's Needs Assessment Work Group oversaw the development of the survey instrument, and staff from Public Health – Seattle & King County were responsible for survey distribution, collection and analysis.

The Planning Council sought to collect information on a wide spectrum of persons living with HIV/AIDS in King County, ranging from individuals who were HIV positive but not yet symptomatic to persons with end-stage illness. The process emphasized traditionally under-served populations, including persons who were homeless, were dually or triply diagnosed (with HIV and mental health or substance use histories), women, youth/young adults, persons of color and persons living in South and East King County. Survey forms were created both in English and Spanish language versions.

The survey inquired about 36 types of HIV/AIDS-related services offered in the King County Continuum of Care. Consumers identified each service either as one that they needed and used, did not need, or needed but could not get. For services that were identified as "need, but cannot get," consumers were asked to identify the reason(s) why this service was unavailable. The survey also asked consumers to choose up to seven of the services that they would consider most important for them.

In response to an increased focus on medical care access by the Health Resources Services Administration (HRSA), the Planning Council added a new component to the 2001 survey. The survey asked consumers to identify the services they felt were most important in helping them access or maintain medical care ("access services"). The survey also collected demographic information, as well as information related to HIV health status and medication adherence issues.

In creating the survey instrument, the Planning Council made extensive efforts to safeguard the anonymity of survey respondents. Survey instructions explicitly stated that consumers should not include their names, addresses or phone numbers on return surveys. To further safeguard respondents' confidentiality, the surveys were pre-addressed to the "Planning Council," rather

than the "HIV/AIDS Planning Council" or "Public Health – Seattle & King County." Survey forms were bar coded for pre-paid reply.

To reach as broad a range of consumers as possible, survey distribution sites included 65 service agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed at the offices of 34 private medical care providers and 11 private dentists. Public Health delivered a total of 2,700 surveys to the various agency and provider sites. Based on follow-up inquiries of agencies and providers, between 1,585 and 1,878 surveys were actually distributed to consumers. The Planning Council received a total of 538 valid responses, for a return rate of between 27% and 32%.

Efforts to reach traditionally underserved populations appeared to be successful. Survey demographic data indicate that 14% of respondents were women versus 9% of estimated King County PLWH, 27% of respondents were people of color versus 26% of PLWH estimates, and 12% of respondents identified heterosexual contact as the primary mode of HIV exposure versus 5% of PLWH estimates. The survey also appeared to be effective in reaching South and East King County PLWH, with 20% of respondents listing a non-Seattle zip code, comparable to estimates suggesting that 18% of King County PLWH live outside Seattle.

Additionally, 11% of respondents reported being homeless within the past year, 7% reported having been incarcerated within the past year and 30% of respondents reported having been diagnosed with a mental illness. Each of these percentages represents an increase over those reported by consumers on the 1999 survey.

As in previous years, however, two populations appear to have been under-represented among survey respondents: persons between 20-29 years of age (9% of survey respondents versus 23% of King County PLWH estimates) and heterosexual injection drug users (3% of respondents versus 7% of PLWH). Younger PLWH are less likely to know their serostatus, which may explain the low response rate among this cohort. The low percentage of self-identified injection drug users may represent under-sampling of this population or may indicate that respondents were not willing to disclose histories of substance use on the survey form. If the latter is true, this may correlate with the high percentage of respondents who reported heterosexual contact as their primary mode of transmission (12% of survey respondents versus 5% of PLWH estimates).

B. Provider Surveys

The Planning Council created and distributed a provider survey as another component of the 2001 assessment process. The Council believes that service provider data offers important comparisons to consumer-identified service priorities and gaps, as well as helping to gather input about sub-populations that may not have been effectively represented among consumer survey respondents. (See Appendix E for a copy of the provider survey instrument.)

The survey collected information from as broad a range as possible of providers of service to persons living with HIV/AIDS in King County as possible. These included primary care

providers, case managers, providers of non-Western therapies, private dentists, substance use and mental health treatment professionals and staff from human service agencies throughout King County.

Public Health distributed provider surveys at 59 agencies, community organizations, and health care facilities throughout the county. Surveys were also distributed to 40 private doctors and 11 private dentists.

The survey inquired about the type of service offered by the provider, the total number of persons with HIV/AIDS on the provider's current caseload, and demographic breakdowns related to the provider's HIV/AIDS clientele. Using the same list of 36 HIV/AIDS-related services that appeared on the consumer survey, providers were asked to identify up to seven services that they believed were most important for their client populations. The survey also asked providers to check each service that they felt was needed by a substantial number of their clients, but that clients were having trouble accessing, and to identify the top seven services that the provider believed helped his/her clients to access or maintain medical care.

Public Health delivered a total of 561 surveys to the various provider sites. The Planning Council received a total of 254 valid responses, for a return rate of 45%.

Efforts to reach providers of traditionally underserved populations were very successful. Survey responses indicate that 18% of the overall consumer population served by responding providers were female (versus 9% of estimated King County PLWH) and 29% of the clients served were people of color (versus 26% of PLWH estimates). Additionally, 37% of the providers' clients identified exposures other than male/male sex (versus 30% of PLWH estimates). Providers also reported seeing a higher percentage of youth and young adult PLWH (12% of the survey respondents' caseloads versus 1% of King County PLWH). Additionally, providers reported that an average of 15% of their clients had been homeless within the past year, 11% had been incarcerated within the past year, 46% had a history of chemical dependency and 37% had been diagnosed with a mental illness. These figures also represent increases from percentages reported by providers on the 1999 survey.

C. Consumer Focus Groups

The needs assessment process included eleven focus groups to gather in-depth qualitative information from specific sub-populations of persons living with HIV/AIDS in King County. The questions posed to participants focused on access to medical care (both at time of initial HIV diagnosis and currently), service needs, gaps in services, and overall impressions of the HIV/AIDS care service delivery system in King County. (See Appendix F for a copy of the focus group script.)

Focus groups were held with the following sub-populations of PLWH:

African Americans	Men who have sex with men (MSM)

East King County PLWH
Homeless persons
Injection drug users (non-MSM)
Latinos (conducted in Spanish)
Native Americans
MSM/IDU
South King County PLWH
Women
Youth and young adults

The focus group strategy acknowledges that specific sub-populations of PLWH may present unique utilization patterns, access barriers and service gaps, and addresses the concern that written surveys might not be as well suited to capture information from members of several of the sub-populations. A total of 81 PLWH attended the eleven focus groups.

Based on input from providers of services to Asian/Pacific Islander PLWH, Public Health attempted to conduct one-on-one interviews with members of this population in lieu of a focus group. Providers noted that linguistic differences, as well as client concerns about safe-guarding their anonymity, make recruitment for a focus group extremely difficult. Unfortunately, only two Asian/Pacific Islander PLWH expressed interest in being interviewed. Because it would be difficult to generalize information from these individuals to the population of A/PI PLWH as a whole, the interviews were not conducted. Public Health will work with the Planning Council to explore potential means of gathering more useful data from this population in future assessments. As a result, information regarding service utilization and needs of A/PI PLWH are limited in this report to quantitative data from consumer surveys and key informant interviews of service providers to this population.

Service providers across the Continuum of Care disseminated information about the focus groups within the targeted communities, identified potential participants, and secured appropriate meeting spaces. Provider "hosts" were also invited to attend the focus group to assist in creating a safe environment for the participants. In five of the eleven groups, the providers felt that group members might be more candid without them present, and they chose not to remain after the initial introductions.

Participants received $20 for their time, as well as reimbursement for transportation and/or child care expenses incurred. Staff recorded each of the groups on audiotape. In addition, a non-participant observer took written notes at each group to assist in the final transcription.

D. Provider Interviews

In order to capture qualitative information about clientele and service trends, staff from Public Health – Seattle & King County interviewed 34 HIV/AIDS care service providers in King County. The providers supplied demographic information about their client population and identified trends or changes that they observed in their clientele. Providers also noted the types of HIV/AIDS-related care services that their clients most frequently utilized, as well as identified access barriers and system gaps in service delivery experienced by their clients. (See Appendix G for a copy of the provider interview form.)

As with the focus groups, providers were identified based on their affiliations with specific sub-populations of PLWH. The interview roster included medical providers with large HIV/AIDS caseloads (representing private, clinic and hospital-based practices in Seattle, East and South King County), case managers, mental health providers, substance use treatment facility staff, and jail health staff. Public Health staff also interviewed service providers at several King County community-based organizations (including organizations targeting women, persons of color, youth/young adults, and homeless persons). Each interview lasted between forty-five and ninety minutes. Although most interviews were conducted with individual providers, some providers were interviewed in pairs.